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Award Number: W81XWH-12-1-0589

TITLE: Cognitions, Decisions, and Behaviors Related to Successful Adjustment among Individuals with SCI: A Qualitative Examination of Military and Nonmilitary Personnel

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REPORT DATE: OCT 2014

TYPE OF REPORT: Annual Report

PREPARED FOR: U.S. Army Medical Research and Materiel Command
Fort Detrick, Maryland 21702-5012

DISTRIBUTION STATEMENT: Approved for Public Release;
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REPORT DOCUMENTATION PAGE				Form Approved OMB No. 0704-0188	
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1. REPORT DATE October 2014		2. REPORT TYPE Annual		3. DATES COVERED 30 SEP 2013 – 29 SEP 2014	
4. TITLE AND SUBTITLE Cognitions, Decisions and Behaviors Related to Successful Adjustment Among individuals with SCI: A Qualitative Examination of Military and Nonmilitary Personnel				5a. CONTRACT NUMBER	
				5b. GRANT NUMBER W81XWH-12-1-0589	
				5c. PROGRAM ELEMENT NUMBER	
6. AUTHOR(S) Michelle A. Meade email:mameade@med.umich.edu Bradley L. Trumpower				5d. PROJECT NUMBER	
				5e. TASK NUMBER	
				5f. WORK UNIT NUMBER	
7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES) The Regents of the University of Michigan. 3003 South State Street Ann Arbor, MI 48109-1272.				8. PERFORMING ORGANIZATION REPORT NUMBER	
9. SPONSORING / MONITORING AGENCY NAME(S) AND ADDRESS(ES) U.S. Army Medical Research and Materiel Command Fort Detrick, Maryland 21702-5012				10. SPONSOR/MONITOR'S ACRONYM(S)	
				11. SPONSOR/MONITOR'S REPORT NUMBER(S)	
12. DISTRIBUTION / AVAILABILITY STATEMENT Approved for Public Release; Distribution Unlimited					
13. SUPPLEMENTARY NOTES					
14. ABSTRACT This project is designed to find out how successful adjustment happens after SCI. Successful individuals will be identified through a survey. Those individuals (both those from military backgrounds and others) are being recruited to take part in an in-depth qualitative interview to help identify key factors in successful adjustment after SCI. The project has received 548 responses to date from 3 of 4 recruitment sites. The final recruitment site is in process and will be completed during the next project year. We have also begun to analyze the data and to begin recruitment for the qualitative phase of the study.					
15. SUBJECT TERMS Spinal cord injury, resilience					
16. SECURITY CLASSIFICATION OF:			17. LIMITATION OF ABSTRACT	18. NUMBER OF PAGES	19a. NAME OF RESPONSIBLE PERSON
a. REPORT	b. ABSTRACT	c. THIS PAGE			USAMRMC
U	U	U	UU	10	19b. TELEPHONE NUMBER (include area code)

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Introduction

This project is designed to find out how successful adjustment happens after SCI. We have started by identifying “successful” and resilient individuals with SCI via a mail survey to the known population of individuals with SCI served by the associated project sites (phase 1). We will then recruit a stratified sample of successful individuals and use qualitative techniques to gather details from them about their lives and experiences (phase 2). We are focusing these qualitative interviews on finding out about the thoughts they had, the decisions they made and the behaviors they performed in the first few years after injury, as well as what factors influenced these. By illuminating the process of positive adjustment and successful self-regulation after SCI and articulating specific and concrete cognitions, decisions and behaviors, this project will provide foundational information to enhance existing intervention and develop new assessments and programs.

Body

The research study team has made the following progress on the Statement of Work tasks during Year 2 of this project. Please note the adjustments to the project months for the tasks. We intend to request a six month no cost extension in order to complete the project.

Task 1: Maintain regular contact with Funding agency and Advisory Board

Both Dr. Meade and Mr. Trumpower have been in regular contact with DoD personnel, particular Ms. Lori Walthers. Contact with our Advisory Board has occurred over the phone, through e-mail and in person.

1a. Attend and participate in program review meetings in Washington DC area (years 1 and 3)

- The meeting in Y1 was cancelled. Planning to attend in Year 3.

1b. Attend and participate in DoD Sponsored scientific meeting

- Planning to attend this year. However, attendance at and preparation for this meeting may be contingent on being provided with details in sufficient time to make the need preparations.

1c. Complete all grant related progress reports

- All progress reports have been completed and submitted.

Task 2: Complete all necessary regulatory review and approval processes for research involving human subjects (months 0 to 6; month 13; month 24)

This project involves two phases (mail survey and qualitative interviews) which have been submitted as two separate studies to the University of Michigan IRB. In addition, the mail survey (phase one) study has been submitted to the IRB at the Rehabilitation Institute of Michigan and the Ann Arbor VA. While the DoD considers the Paralyzed Veterans of Michigan (PVA) as its own site, it does not have an IRB and so is included

under the University of Michigan IRB. As approvals have been received from a site, the paperwork has been submitted to the DOD.

- University of Michigan Phase I is approved until: 8 January 2015.
- University of Michigan Phase II is approved until: 4 February 2015.
- Phase II (A-17615.2) approved by DOD HRPO on 5 February 2014
- RIM received approval for the mail survey on 20 September 2013.
- Ann Arbor VA initial approval was on 15 April 2014 and re-approved on 19 September 2014

Task 3: Finalize Screening Survey (months 1-4)

- Completed in previous year

Task 4: Conduct Screening Survey (months 17-23 & 25-27 (VA))

4a: Develop or Review and finalize mailing lists at all sites

- Development and review of the mailing list for the Ann Arbor VA is in process.
- All mailing list activity for the other sites has been completed.

4b: Print / copy postcards, envelopes and survey instruments

- Items for the Ann Arbor VA will be printed as soon as the mailing list has been reviewed and we have an accurate count.
- All other mailings have been completed.

4c. Establish web survey

- Completed in the previous year

4d: Create / compile survey packages for distribution to various sites

- Completed for UM, RIM, and MPVA)

4e. Where possible (UM, RIM, AAVA), track survey number by matching it with name on mailing / recruitment list

- Tracking completed for applicable sites

4f. Conduct 4-part mailing – notification post card; survey; reminder post-card; second survey

- 4-part mailing has been completed for UM and RIM.
- Further mailings to MPVA participants were cancelled when an issue was discovered with the mailing list the MPVA was using. It contained names of all of their members and not just those with a spinal cord injury. The MPVA list received the initial postcard, 1 copy of the survey, and the reminder card. They were not sent the second copy of the survey.

4g. Track and enter information from returned surveys into REDCap database (UM Research assistant)

- All data has been entered into the Qualtrics database. Qualtrics replaced REDCap for this purpose.

Task 5: Review and analyze data (months 23-30)

5a. Review of data by study investigators

- Data review has begun (Y2Q3-Y2Q4). Publications are being prepared.

5b. Classification of respondents into categories based on military background, level of resources, and time since injury as well as based on responses of adjustment measures.

- Initial review and classification of responders has been completed; this will be updated once surveys are received from AAVA participants. Specifically, it was decided by the team of investigators, that potential participants would be identified as “successful” based on their responses to the Flourishing Scale.
- 530 individuals returned surveys with that provided valid scores on the Flourishing scale
- 153 individuals had scores within the top quartile (49 or over) on the Flourishing scale
- 207 individual had scores within the top third (48 or over) on the flourishing scale
 - Of Those, 151 individuals answered yes or maybe when asked if they would be willing to participate in an in-depth interview; given the diversity of characteristics of this group, it appears that we should be able to recruit a stratified sample of individuals
 - Military background: 53 respondents (35.1%) reported having a military background
 - Gender: 113 male; 36 female (2 missing)
 - Years since Injury: 60 of these respondents had been injured for less than 10 years at the time they completed the survey
 - Income: 16 of these respondents reported having a household income of less than \$20,000 a year and another 16 reported a household income of less than \$30,000 per year; 46 respondents reported household incomes of \$80,000 and over
 - Level of Injury of these respondents ranged from high-level tetraplegia (n=24) to a lumbar or sacral injury (n=20)

5c. Extraction of data into SPSS for analysis and dissemination

- This task will continue as needed for publications. The SPSS data file will be updated once information from participants from the Ann Arbor VA are received.

Task 6: Finalize semi-structured interview and assessments for in-person interviews (Months ~~9 to 12~~ 15-16)

6a. Meet with advisory board to finalize content and focus of interview

- The advisory board met to finalize this interview. The interview was revised and the amended interview was submitted to University of Michigan IRB and received approval. It was also reviewed by the DoD and it was decided that additional review and approval is not needed.

6b. Practice / pilot semi-structured interview to ensure clarity and comprehensiveness

- Completed

Task 7: Select and recruit stratified sample of individuals with SCI who demonstrate “Successful Adjustment” for in-depth qualitative interviews (months ~~12-13~~ 22-30)

7a. Identify potential participants for the in-depth interviews from the pool of individuals who completed the screening survey based on their responses; at least five individuals should be identified and recruited in each of the 12 boxes, for a total of 60 participants.

- Potential participants from three of the four sites (UMich, RIM and MPVA) have been identified based on their responses to the survey and recruitment is in process. As we are still awaiting access to and responses from potential participants from the Ann Arbor VA, we will conduct our first interviews with individuals without military backgrounds and then move on to individuals with military backgrounds. It should be noted, though, that even though we have not yet recruited through the Ann Arbor VA, our survey has still identified 177 potential participants with military backgrounds, 53 of whom also have high flourishing scale scores and indicated that they were or might be willing to participate in the in-depth interview.

***the remaining tasks will be completed in Year 3 or NCX Year 4 of the project**

Task 8: Conduct in-depth interviews with 60 “successful” individuals with SCI (months ~~13 to 24~~ 25-36)

8a. Schedule and conduct in-depth individual interviews with 60 study participant with SCI with military and non-military backgrounds at times and locations convenient to the participants.

8b. Record interviews using audiotape or digitally-recorded devices

8c. Conduct semi-structured interview designed to elicit information pertinent finding out about the cognitions, decisions and behaviors that the participant experienced or engaged in during their first two years after injury.

8d. Collect additional data, including information about demographic, personal and community characteristics and to complete brief assessments of social support, cognitive ability and personality

Task 9: Transcribe, “clean” data from interviews and enter into qualitative software (months ~~13 to 26~~ 26-35)

9a. Send digital recordings of in-depth interviews to a professional transcription service with expertise in medical transcription and transcripts will be returned to the interviewer

9b. Interviewer will compare transcript to the recording as a check on accuracy and completeness. Errors will be noted and corrected and relevant nonverbal communication inserted into the text where appropriate.

9c. Enter “cleaned” transcripts into qualitative software to facilitate the processing and analysis

Task 10: Develop Coding Book (months ~~13 to 19~~ 26-36)

10a. Develop index system and coding scheme, based on theoretical concepts embedded in the research questions and precise and standard definitions and examples to ensure that individual coders consistently apply the codes to the narrative text.

Task 11: Code Interviews (months ~~16 to 30~~ 27-40)

11a. Project investigators (C. Duggan and M. Meade) will review and code the text of the transcribed interviews, reducing and organizing non-numeric data for qualitative analysis; consultant (C. Wilson) will review select transcripts as additional check and to assist with resolving differences in coding

11b. Update and modify coding book to ensure there is detailed documentation of the procedures, decisions, and rationale for decisions made, which should support consistency, dependability, and duplicability of results.

Task 12: Analyze Qualitative Interviews (months ~~20 to 36~~ 27-42)

12a. Matrices of narrative data will be constructed based on the major research questions posed.

12b. Matrices will be analyzed using the constant comparative method to note similarities/dissimilarities in between group data and search for themes and patterns. In particular, matrices will be used to determine if there are specific behaviors or actions that are performed by successful individuals with SCI related to (a) health / health management; (b) relationships and social support; and (c) employment and community re-integration.

12c. Compare and contrast the cognitions, decisions and behavioral outcomes of military veterans and civilians with SCI, (2) to describe more fully how these cognitions impact decisions and behavioral outcome, and (3) how internal and external factors (psychosocial and environmental characteristics) relate to cognitions.

12d. Conduct quantitative comparisons of information related to demographic characteristics, cognitive ability and personality in order to obtain additional information about the process of successful adjustment.

12e. Interpret results of analysis. Investigators will be meeting frequently to discuss findings and possible interpretations.

Task 13: Receive feedback on interpretations (months ~~16 to 36~~ 37-42)

13a. Discuss interpretations with consultants and advisory board members and incorporate their feedback into summary of findings.

13b. Use Community participatory research strategies to engage participation in interpretation of data by scheduling and conducting three community forums in locations throughout Michigan; feedback and discussion will be recorded, transcribed, and discussed with advisory board and ultimately incorporated into summary of findings.

Task 14: Finalize conclusions, disseminate and begin utilization of project data (months ~~30 to 36~~ 39-48)

14a. Write summary of findings

14b. Conduct presentations to individuals with disabilities and disability organizations throughout Michigan

14c. Apply to present at national conferences related to rehabilitation medicine and SCI

14d. Begin preparation of manuscripts for publication in referred journals; a minimum of 4 peer reviewed publications are expected to result from this project

14e. Begin development of new assessment instruments, programs and psychological and medical interventions based on project findings.

Key Research Accomplishments

- Mailed surveys to 1890 individuals with Spinal Cord Injury, at least 152 of which were returned because of bad addresses or ineligibility. We received completed surveys from 548 individuals – for a 31.5% response rate.
- This is the first study that we know that has used the Flourishing scale with individuals with SCI. As responses to the Satisfaction with Life Scale (SWLS) were also collected, this data will be useful in supporting a more positive focus on life after SCI.
- Almost half of survey respondents (n=252; 46%) took the time to add write-in comments to the question “Is there anything else about resilience that you wanted to tell us?” This level of response suggests that the survey questions resonated with those who bothered to complete them, such that they took the extra time needed to consider and write about their perspective as opposed to just checking a box. We are currently in the process of using qualitative techniques to analyze these write-in responses.

Reportable Outcomes

Survey responses were received from 548 individuals with spinal cord injury. Initial review of responses suggests that we should be able to identify and recruit a sufficiently stratified sample of individuals (based on military background, income, time since injury and level of injury) who have adjusted well following SCI so as to complete the 60 qualitative assessments. We are in the process of analyzing responses to both quantitative and qualitative responses to the survey for dissemination as posters, presentations and articles.

Conclusion

There are a significant number of individuals living well with Spinal Cord Injury. While it is possible that respondents to our survey do not necessarily reflect the entire population, their responses assert that living establishing a good life and flourishing after SCI is possible. We are looking forward to conducting the in-depth interviews, which will provide much more information both about individual cognitions, decisions and behaviors and how those related to current positive outcomes in addition to identifying the potential role of personality and cognitive flexibility in this process.

References

None

Appendices

Not applicable